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New understandings of fathers' experiences of grief and loss following stillbirth and neonatal death: a scoping review

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# Journal Pre-proof

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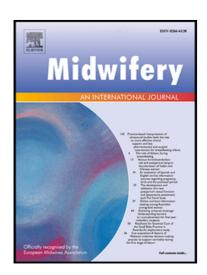
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# Highlights

- Existing research shows that perinatal loss has a profound psychological impact on fathers
- It is evident that there is a need for more cross-cultural research in this area.
- There is a need to understand how perinatal loss impacts on men's health and wellbeing.



# New understandings of fathers' experiences of grief and loss following stillbirth and neonatal death: a scoping review

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### **Abstract**

Objective: To report on research conducted on men's experiences of grief and loss following stillbirth and neonatal death in high-income, Western countries.

Design: This review was guided by the following research questions: 1. The impact of perinatal death for men 2. The meaning of the loss for a father's sense of identity 3. The extent to which men were able to express grief while supporting their partners and, 4. how men's experience of grief was mediated by the support and care received by health professionals.

Data Sources: We searched the following databases: Medline; PsychINFO; CINAHL to identify relevant articles published from the year 2000 onwards. The searches were run between 1/04/2018 and 8/4/2018.

Review methods. A scoping review was conducted of nursing, psychological, medical and social science databases using these key words: fathers' grief, men's grief, perinatal loss and death, stillbirth and neonatal death.

Results. Studies indicated that men reported less intense and enduring levels of psychological outcomes than women but were more likely to engage in avoidance and coping behaviours such as increased alcohol consumption. Men felt that their role was primarily as a 'supportive partner' and that they were overlooked by health professionals.

Conclusions. Further research is needed on men's experience of grief following perinatal death, especially on their physical and mental well-being.

Impact: This review addressed the problem of the lack of knowledge around paternal needs following perinatal death and highlighted areas which researchers could usefully investigate with the eventual aim of improving care for fathers.

Key words: Fathers, grief, loss, neonatal death, stillbirth

# 1.0 Introduction

Despite improvements in maternity health care services and neonatal intensive care units in the last few decades, the latest available figures from the Office for National Statistics (ONS) indicate that in 2016, 5544 babies in the UK were stillborn or had died in the first four weeks of life (early neonatal death). In 2016, 1 in every 227 babies delivered in the UK was stillborn (died during pregnancy from the 24<sup>th</sup> week of gestation) while 1 in 370 babies died in the early neonatal period (ONS, 2018). Internationally, there are over 4 million perinatal deaths each year (Flenady et al., 2014). Bereavement following such losses is associated with adverse mental health outcomes for parents such as anxiety, depression, post-traumatic stress disorder (PTSD) and risk of suicide (Turton et al., 2006; Kagami et al., 2012; Redshawe et al, 2014). Research on perinatal death has been dominated by studies utilizing psychological measures and assessments to measure the extent of parental grief (e.g. perinatal grief scale, Toedter et al., 1988). While citing the existence of cultural and social

norms that encourage male internalisation of emotions, the outcome of these studies has broadly confirmed the assumption that men are less affected than women, who experience higher levels of grief (Christiansen, 2017; Christiansen et al., 2014). Bonnette and Broom (2012) have argued that there are questions about the extent to which measurements of grief are sensitive to 'male' forms of expression.

### 2.0 Background

One of the consistent findings of research on masculinities is that men tend to be less emotionally expressive than women (Doucet, 2006; Dermott, 2008). This apparent lack of emotion is closely linked with dominant social expectations around 'being a man'. One consequence of this is a reluctance among some men to share their problems with others, including professionals. Research by Robb and Ruxton (2018) with young men found that, when it came to dealing with emotional problems, some claimed that they would find specifically 'masculine' ways of dealing with them, for example, by disconnecting from others such as partners in order to appear 'manly'. As a consequence this can lead to a deterioration of a father's mental health, leading to a higher risk of alcohol and substance misuse (Ashbourne et al., 2013).

Studies which focus specifically on men's experiences of loss following perinatal death have illustrated the complex tension between 'grief expression' and 'supportive carer'. They demonstrate how grief and trauma following perinatal death are situated within gender relations such that some men may internalize their grief in order to support, protect and to be strong for their partner (Bonnette and Broom, 2012; O'Leary, 2005b). Experiences of loss, then, are situated within wider socio-cultural expectations about the 'male role' which encourage men to perform stoic roles by silencing their own anxiety and grief in order to be strong for their partners following stillbirth and neonatal death (Samuelsson et al, 2001).

Yet studies of fatherhood have demonstrated how important it is for men to claim paternal identity and the transformative impact of fatherhood on men's sense of themselves as men (Robb, 2004; Doucet, 2006; Dermott, 2008). More recent research by Robb and colleagues (2018) revealed that most men, even those whose own experience of family relationships may have been fractured, aspire to become fathers, and take the responsibilities of fatherhood seriously.

Indeed, research concerning fatherhood, identity and perinatal loss demonstrates that before birth men experience fatherhood by anticipating and acknowledging the child during pregnancy (Marsiglio et al., 2013). Obstetric practices such as ultrasound scans, prenatal diagnostic procedures and prenatal classes can add to the sense of the personhood of the baby and therefore identification as a

father and attachment to the unborn infant (Bonnette and Broom, 2012; Hockey and Draper, 2005). The more active and significant role of contemporary fathers in parenting is a factor likely to impact on the intensity of grief (Doucet, 2006; Dermott, 2008). However, despite the identity work which occurs before birth, a significant source of distress for men is the ambiguity of fatherhood when a baby dies (Cacciatorre et al., 2008b;). This is further exacerbated when fathers describe being overlooked by healthcare providers who are more focused on the mother's welfare (McCreight, 2004; O'Leary &Thorwick, 2005).

The importance of providing good quality support and care following perinatal death has been demonstrated and emphasised through the development of a series of guidelines to support parents after loss (Kingdon et al, 2015; SANDS, 2016). What constitutes best practice especially in relation to psychosocial care has been debated (SANDS, 2016). Some practices such as holding the baby have been reviewed and even discouraged due to reports of adverse outcomes such as PTSD (Burden et al., 2016), although other studies have suggested there are some benefits (Kingdon et al., 2015). Indeed, Samuelsson et al. (2001) argue that men in their study appreciated an opportunity to actively mourn their child by seeing and holding their baby and collecting mementoes.

The aim of this scoping review was to explore men's experiences of the loss of their baby in the immediate post-natal period and their experiences of ongoing support in order to inform future thinking on recommendations, interventions and priorities for new research.

# 3.0 The Review

This review was guided by the following research questions: 1. The impact of perinatal death for men 2. The meaning of the loss for a father's sense of identity 3. The extent to which men were able to express grief while supporting their partners and 4. how men's experience of grief was mediated by the support and care received by health professionals.

# **3.1** Aims

We set out to map the existing literature that constitutes the evidence base in what is a complex and heterogeneous field of research, and to determine the potential for conducting primary research (Levac et al., 2010) specific to men and grief. The scoping process requires analytical reinterpretation of the literature in a field where there is a paucity of randomised control trials. A scoping review thus represents a way to examine the extent, range and nature of research activity, identify gaps in the

literature and clarify a complex concept such as the emotional experiences of men following perinatal death.

### 3.2 Design

In undertaking the review, we used the Levac et al., (2010) methodological framework, an approach which has been further developed following a review of scoping studies conducted by Arksey and O'Malley (2005). Throughout this process we followed a six-stage methodological framework: identifying the research question; searching for relevant studies; selecting studies; charting the data; collating, summarizing, and reporting the results.

Unlike a systematic review, a scoping review formally documents the research that has been undertaken since 2000 without providing detailed critical appraisal of the individual studies. Scoping reviews can also identify research gaps in the existing literature. The rationale for selecting to search the literature which is available from 2000 onwards is that there is widespread recognition that the typical timescale demanded to conduct a rigorous systematic review is unsuited to the timescale and funding available to some scholars (Grant and Booth, 2009). Given that the timescale for conducting this review was also limited by time and resources the search of the literature was confined to 2000 onwards.

### 3.3 Search methods

To identify relevant studies in the medical and psychosocial literature we searched the following databases: Academic Search Complete and PsychINFO. We identified all relevant articles on a) perinatal death b) men's experience of grief c) parental experiences of grief and used the primary search terms "perinatal loss and father", "perinatal death and fathers", stillbirth and men", "neonatal death and men" coupled with secondary descriptors of "infant death and father". We screened the titles and abstracts of all articles retrieved through the initial database search and then obtained the full texts of all studies that could potentially meet the inclusion criteria. Full text articles were then examined in detail by two reviewers (reviewer 1 and reviewer 2) who worked independently to determine whether the study met criteria for inclusion in the review. Any disagreements were referred to a third reviewer.

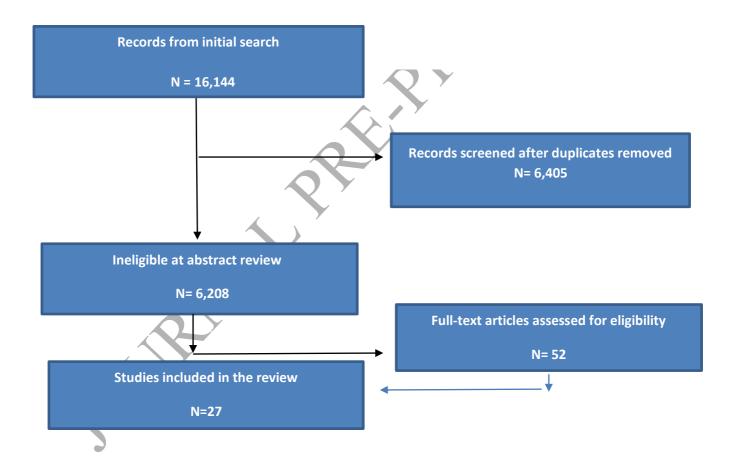
We also checked the reference sections of all included studies for potentially relevant papers. Other reasons for exclusion were: a) duplicates, b) topic not relevant to stillbirth, c) impact on healthcare

professionals not parents, d) review articles, e) year of publication, or f) dissertations. Reference lists were scanned for additional studies.

# 3.4 Search outcome

The search of the electronic databases retrieved 16,144 records. The study flow for the review is shown in Figure 1. Fifty two full paper copies of publication records were assessed for inclusion in the review and screened to identify further relevant research.

Figure 1. Flowchart of the study selection process.



### 3.5 Quality Appraisal

The aim of this scoping exercise was to map the extent of the literature that existed from 2000 in relation to men's experience of perinatal death, rather than assessing the quality of the studies that were identified. Heterogeneity among the types of studies included, as well as the measures used to assess outcomes, precluded an effort to summarise quantitative data across studies in the form of any generic effect size measures.

While this scoping review follows a similar methodological step as a systematic review a key difference is that quality assessment is not included since an assessment of what constitutes quality differs. This review was more concerned with the research findings themselves (many of which are qualitative in design), rather than on the means of obtaining them. Therefore, an analysis of the strength of studies considered was not performed. However, this review recognises the potential for bias because of the limitations in rigour and that the conclusions are based on the existence of studies rather than on the quality used to generate conclusions (Grant and Booth, 2009). Yet, scoping reviews such as this can identify implications for practice and inform policy makers as to whether a full systematic review is needed (Grant and Booth, 2009; Levac et al, 2010; Peterson et al, 2017).

While we recognised the strength of generating conclusions by conducting a systematic review, a scoping review was undertaken due to time and funding constraints. We also recognised that while a scoping and systematic review begins with a primary research question as its focus, a scoping review allows for a more general question and exploration of the relevant literature as opposed to providing answers to a more limited question. A scoping review, therefore, permits a broader conceptual range (Arksey and O' Malley, 2005; Peterson et al, 2017) and also provides more flexibility than a systematic review since it is able to account for a diversity of literature and studies which utilise different methodologies (Arksey & O'Malley, 2005; Levac etal, 2010).

# 3.6 Data abstraction

Papers included in the review were read in full and summarized within a data extraction sheet according to their aim, participants, method of data collection and analysis, setting, outcomes and authors' conclusions.

The inclusion and exclusion criteria were set to optimise the number of relevant studies chosen for inclusion and we considered articles written in English from Western, high-Income countries: the UK, Europe, North America and Australia. Studies from countries where health care provision and

cultural and religious practice were likely to be substantially different were excluded. As international definitions of stillbirth and neonatal death vary and many papers explored a combination of foetal loss types and various gestational ages, it was decided to exclude studies which exclusively examined miscarriage, foetal loss before 24 weeks, lethal foetal abnormalities and Sudden Infant Death Syndrome (SIDS). We excluded studies prior to 2000 to ensure that the most relevant and recent accounts of loss were explored. Conference abstracts, dissertations, books, essays, editorials, commentaries and audio accounts were excluded. We included quantitative, qualitative, mixed methods studies and systematic reviews which assessed and explored parental experiences of perinatal death or health care professionals support and care following perinatal death including subsequent pregnancy and the impact of a previous perinatal death.

### 3.7 Synthesis

The findings identified were read by both reviewers independently and study details were documented in a tabular form and in a narrative synthesis. The findings were then analysed thematically and guided by the research questions. Any contradictions were discussed by two of the researchers (reviewer 1 and 2) and disagreement resolved by a third reviewer.

### 4.0 Results

Twenty-seven studies met the inclusion criteria. Details of the included studies are documented in Table 1. The searches were restricted by publication date (2000 onwards only) and all research identified had been published in the last 18 years, as Table 1 shows.

# Table1. Summary of characteristics of included studies

	Study reference	Aims of study	Participants	Method of data collection	Method of analysis	Findings	Setting & Context	Country
1	Christiansen, D.M. (2017)	Systematic review of posttraumatic stress disorder in parents bereaved by infant death		46 articles based on 31 studies of PTSD	Systematic review of quantitative, statistical analysis	Generally, PTSD prevalence levels much lower in fathers than in mothers. PTSD symptoms not found to differ much re timing of death (prior, during or post)		Denmark
2	Ellis,A., Chebsey,C., Storey,C., Bradley, Jackson, Flenady, V.,Heazell,A.,& Siassakos,D. (2016)	Systematic review of parents' and healthcare professionals' experiences of care after stillbirth in high-income Westernised countries. Aim of review to inform research, training and improve care for parents who experience stillbirth	Ź	Systematic review of 52 qualitative, quantitative and mixed-method studies	Synthesis and quantitative meta- summary – to calculate frequency effect sizes for each theme	Findings relating to fathers - Fathers found to have different needs. Other findings (for both parents)highlighted lessons for staff - eg discuss concerns, give options and time, privacy not abandonment		Studies pertaining to high-income Westernised countries
3	Burden, C., Bradley, S., Storey, C., Ellis, C., Heazell, A., Downe, S., Cacciatore, J., & Siassakos, D. (2016)	Systematic review to evaluate and summarise current evidence regarding the psychosocial impact of stillbirth to parents and their families, in order to improve guidance in bereavement care worldwide		Systematic review of 144 qualitative, quantitative and mixed-method studies	Synthesis, and quantitative meta- summary - to calculate frequency sizes for each theme (as a measure of their prevalence in the literature)	General themes were identified, but themes particularly prominent for fathers – grief suppression, employment difficulties, financial debt, and increased substance use. Focus of consequences may vary with parent gender and country		All languages and countries included
4	Wilson, P. A., Boyle, F. M. and Ware, R. S. (2015),	To document parents' experiences and outcomes in relation to seeing and holding a stillborn baby at a	26 mothers and 11 fathers who experienced a	Mailed self-report questionnaires completed at 6-8 weeks and 6 and	Validated measures assessed regret regarding the decision to hold	Mothers and fathers reported poorer mental health but small numbers mean estimates	Via a Brisbane Hospital with a	Australia

		hospital with a specialist perinatal bereavement service	stillbirth (between 2007 -2008	13 months postloss	their baby, parental grief and mental health	are imprecise. Conclusions: More intense grief does not equate with poorer mental health for mothers who choose to see and hold a stillborn infant. Fäthers' experiences warrant further study. Supported decision-making is important for bereaved parents, and rigorous evaluation of bereavement care is essential	specialist perinatal bereaveme nt service	
5	Kingdon, C, O'Donnell, E, Givens, J, & Turner, M (2015)	To examine how the approach of healthcare professionals to seeing and holding the baby following stillbirth impacts parents' views and experiences.	Synthesis of 12 papers representing views of 333 parents (156 mothers, 150 fathers, 27 couples) from 6 countries	Synthesis of qualitative studies reporting parental views with gestational loss.	Meta-ethnographic techniques to identify key themes and a line of argument synthesis	Findings advance understanding of how professionals can support parents to make appropriate decisions in a novel and highly charged and dynamic situation	PsychINFO and PubMed	6 high-income, Westernised countries
6	Campbell-Jackson, L, Bezance, J, & Horsch, A. (2014)	To explore mothers' and fathers' experiences of becoming a parent to a child born after a recent stillbirth	7 couples (14 participants) who had experienced stillbirth after 24 weeks of gestation and had gone on to have a live baby (aged under 2 years)	In depth- interviews	Interpretative Phenomenological analysis	5 themes – living with uncertainty, relationship with next child, continuing grief process, identity. Fathers' experiences similar to mothers – high levels of anxiety and guilt. Fathers reported lack of opps for grieving	Recruited from previous study	UK
7	Davidson, D, & Letherby, G 2014,	To explore the use of social networking and online networks following perinatal loss. Part of the 'griefwork online project'	No specific details – anonymous online contributors	Online contributions relating to loss and grief posted on generic information websites and specific information websites	Ethnographic study – produced an ethnographic fiction - quotations' represent ' composite narratives of collective experience 'rather than individual	Not only do mothers, and sometimes fathers and grandmothers, seek support on the Internet but they also engage in grief work (the work the bereaved do with others)	Online	UK

				dedicated to perinatal loss and sites which offer support and encourage positing	accounts.	<b>A</b>		
8	Christiansen, D.M., Olff, M., & Elklit, A. (2014)	To examine sex differences in PTSD following infant death, and sex differences in the relationship between PTSD severity and related variables	361 mothers and 273 fathers who had lost an infant either late in pregnancy, during birth or in the first year of life	Questionnaires between 1.2 months and 18 years after the loss (M=3.4 years).	Statistical analysis	Mothers reported significantly more PTSD symptoms, attachment anxiety , emotion-focused coping and feeling let down, but significantly lower levels of attachment avoidance than fathers. When all variables and time since the loss were examined together, no significant moderation effects of sex . Persistent posttraumatic symptoms exists in both mothers and fathers long after the loss. Several sex differences in severity and correlates of PTSD were identified for attachment and emotion-focused coping. Overall, more similarities than differences were noted	Danish support organization for parents bereaved by infant death	Denmark
9	Cacciatore, J., Erlandsson, K., & Rådestad, I. (2013)	To evaluate fathers' experiences of stillbirth and psychosocial care	131 fathers who had experienced the death of a baby to stillbirth after the 22nd week of gestation between 2000 and 2010.	Electronic Questionnaire via homepage of Swedish National Infant Foundation	Responses to open- ended questions analysed using content analysis	86% fathers reported feeling grateful towards health care professional, 16% reported feeling sad, hurt or angry about something personnel did, fathers expressed gratitude when professionals treated their child with respect and without fear and when their fatherhood was validated. Bereaved	Homepage of Swedish National Infant Foundation	Sweden

						fathers experience overall gratitude for person-centred psychosocial care post stillbirth		
10	Christiansen, D., Elklit, A., & Olff, M. (2013)	To examine chronic PTSD symptoms and potential correlates in mothers and fathers up to 18 years after the death of their infant	634 mothers and fathers (57% female)	Questionnaire package including measures of PTSD, coping, perceived social support, attachment	Statistical analysis of variance, correlation analyses and regression analysis	Estimated PTSD prevalence of 12%. Type of loss didn't have effect on PTSD severity, but lower gestational age was associated with more symptoms. Study highlights long-term impact of infant loss and points to attachment, coping and social support as important contributors to the development and maintenance of PTSD symptoms	Members of a private national support organization for parents bereaved by infant death were contacted and asked to participate	Denmark
11	Bonnette, S., & Broom, A. (2012)	To explore how men who have experienced stillbirth engaged with their unborn and stillborn child as fathers and the perceived legitimacy of male grief	12 men who have experienced stillbirth	Qualitative interviews	Interpretative traditions (drawing on Charmaz)	Men identify as fathers to their unborn and stillborn child in complex ways. They develop dynamic and ongoing relationships with their child post-stillbirth. Authors identify the problematic of expressing grief in the context of the male role. Cultural constructions of the 'male role' are both manifest and contested in the context of stillbirth, and fathering and grief are situated within a highly gendered and relational dynamic.	purposive and snowball sampling – invitations via community notice boards,libr aries, community centres, pharmacie s and shops and newsletter s of two stillbirth support organizations	Australia
12	Ward, F,R. (2012)	Systematic review of controlled trials from the Cochrane Pregnancy and childbirth group to assess				The reviewers identified impact of PTSD and alcohol use in men and impact on marriage. It		

		professional and counseling support interventions and compare with standard care.				was not possible to make recommendations about the effectiveness of interventions for provision of support to families grieying perinatal death since no studies met the inclusion criteria.		
13	Erlandsson, K., Saflund,K.,Wredlin g,R., & Radestad, I. (2011)	To explore parents' experiences of support over a 2 year period after a stillbirth and it's effect on parental grief	33 mothers and 22 fathers at 3 months, 1 year, after 2 years following a stillbirth	Questionnaire	Statistical analysis	Support from family and friends important 2 years after stillbirth. Need for professional support after stillbirth can differ depending on support from social networks	Recruited via midwife at hospital	Sweden
14	Cacciatore, J., Defrain, J., & Jones, K. (2008a)	To show how both individuals and family members struggle with ambiguities of the loss of their baby and how some negotiate the unpredictability of the loss.	74 mothers', fathers' grandparents' uncles' and aunts.'	Retrospective analysis Germany? of anonymous data with discussion and on line group collected by 2 organisations that provide support to bereaved families	Boss's ambiguous model used for framework analysis	Family members feelings of grief and loss mediated by social environment that is disenfranchising as the loss is not recognized.	By two non-profit organisatio ns that provide care and support to grieving families.	USA
15	Cacciatore, J., Defrain, J., & Jones, K., & Jones. H. (2008b)	To explore the ways in which bereaved parents perceive and cope with the death of their baby and how this affects them individually and as a couple.	74 bereaved individuals invited to participate in the study online through internet based parental support organisation	Retrospective analysis of anonymous data comprising of an online answer based open ended survey	Adapted version of grounded theory using constant comparison.	Mother's and father's grieve individually and together and struggle to cope and find meaning.	By two non-profit organisatio ns that provide care and support to grieving families.	USA
16	Büchi,S., Mörgeli,H., Schnyder, U.,Jenewein,J., Hepp,U., Jina,E., Neuhaus, R., Fauchère,J., Bucher,H., & Sensky, T. (2007)	To assess grief and post- traumatic growth in parents 2-6 years after the death of a premature baby (24-26 gestation) and to evaluate Pictorial Representation of illness and Self-Measure (PRISM) in the assessment of bereavement	54 párents	Assessment of parental experiences during hospitalization and by questionnaires regarding grief, post-traumatic	Statistical analysis	Even after 2-6 years after loss, parents still suffer a lot from bereavement, mothers more so than fathers. Mothers showed more post-traumatic growth than fathers. Adaptation processes after the death		Germany

				growth, affective symptoms and the visual represeantation of the babyand the self		differ depending on gender, with mothers experiencing more intense grief but also more growth than fathers.		
17	Badenhorst, W., Riches, S., Turton, P., & Hughes, P. (2006)	To (systematically) review the available evidence on the psychological effects of perinatal death on fathers	17 studies – qualitative and quantitative studies	Electronic search of CINAHL, MEDLINE and PsycINFO databases 1966 – 2005	Study quality was rated using checklist and main findings summarised	Quality of methodology varied. Qualitative studies described classical grief responses, but less guilt than mothers. Fathers described experiences related to their social role and potential conflict between grieving couples. Quantitative research reported symptoms of anxiety and depression, but at a lower level than mothers. Fathers may develop PTSD following stillbirth. Social role of fathers as carers for their partners needs recognition when planning care for bereaved families		
18	Säflund, K., & Wredling, R. (2006)	To investigate possible differences between couple in their encounter with their stillborn child and the assistance of caregivers during the event and to evaluate parents' psychological well-being 3 months after the stillbirth	22 couples who had experienced a stillbirth	Study-specific questionnaire and a previously evaluated well- being questionnaire used to assess parents' psychological condition	Statistical analyses to detect differences within couples	Couples had feelings of fear when they conceptualized the stillborn child, but all but one couple held their child. Fathers had same strong feelings of warmth, pride, tenderness, and grief as mother when they held their child. 3 months after the event, mothers scored significantly higher on negative wellbeing, lower on positive well-being and lower on	5 hospitals in Stockholm	Sweden

						general well-being than fathers. A majority of mothers, but no fathers were on sick leave 3 months after event. Study suggests mothers and fathers need to be emotionally supported in the encounter with stillborn child		
19	Turton, P., Badenhorst, W., Hughes, P., Ward, J., Riches, S. & White, S. (2006)	To assess the psychological morbidity of fathers subsequent to stillbirth and to test within-couple effects	38 pregnant couples whose previous pregnancy had ended in still birth and 38 matched controls.	Community based cohort with psychological assessments taking place antenatal, at 6 weeks and 1 year postnatally.	Statistical analysis	Fathers in the index group experiences significant levels of anxiety and post traumatic stress disorder in the antenatal period. Father's symptoms were lower than mother's across all time points.	Communit y based cohort	UK
20	O'Leary, J. (2005)	To explore how grief and symptoms of posttraumatic stress disorder (PTSD) are relived during the ultrasound examination following perinatal loss	12 mothers and 9 fathers, between 22 and 34 weeks gestation in the current pregnancy. All of the previous babies had died within the past year with the exception of one family, who had experienced the loss of a full-term baby 4 years in the past, followed by a miscarriage in the last year	Audio taped interviews were conducted individually with the mothers and fathers, lasting approximately 1 to 1.5 hours.	Descriptive phenomenology (drawing on Giorgi)	Parents should be prepared for memories to resurface during this time and health care providers should consider PTSD symptoms a normal phenomenon under these circumstances.  No specific focus on fathers (no comparison)	Parents recruited via a bereaveme nt newsletter, from other parents aware of the study, and by providers at a high- risk perinatal clinic.	USA
21	Kavanaugh, K., Trier, D., Korzec, M. (2004)	To examine parents' descriptions of the ways family and friends supported	62 interview transcripts from 22	A secondary analysis of data from two	Identified all statements relating to issues of support	Parents received emotional support most frequently. Findings from	1 <sup>st</sup> study a convenienc e sample	USA

		them after they had experienced a perinatal loss.	mothers and 9 fathers were examined	phenomenological studies on perinatal loss was performed.	Vaux's theory of social support was used as a framework	the current study provide data for health care professionals to use to provide quidance to family and friends of bereaved parents. mothers were more likely than fathers to need to have their loss validated and to want to have someone to talk to about their experience. limited representation of the paternal response	was selected from three Midwestern hospitals that provide high-risk perinatal care 2 <sup>nd</sup> study - newspaper ad	
22	McCreight, B.,S. (2004)	To describe the experiences of men whose partner had experienced pregnancy loss and to examine attitudes within medical context towards bereaved fathers	14 men and 32 midwives and nurses	Observation within pregnancy loss self-help groups and in- depth interviews with men who attended the groups and midwives and nurses	Narrative analysis	The perception that men have only a supportive role in pregnancy loss is unjustified, and ignores the actual life-world experiences of the men and the meanings they attach to their loss. Recurring themes included: self-blame, loss of identity, the need to appear strong and hide feelings of grief and anger. Male partner's grief should be acknowledged as a valid response by hospital staff and wider community	Pregnancy loss self- help groups	Northern Ireland
23	Vance, JC; Boyle, FM; Najman, JM, Thearle, MJ. (2002)	To examine patterns of anxiety, depression and alcohol use in couples following stillbirth, or neonatal death	138 bereaved and 156 non- bereaved couples	Standardized interviews using Delusions Symptoms States Inventory (DSSI) at 2,8,15 and 30 months post loss	Statistical analysis	Bereaved couples were more likely than non- bereaved couples to have at least 1 distressed partner. Rarely were both partners distressed. In bereaved couples, mother only distress declined from 21%=10%, father only		Australia

						distress ranged from 7%-15%, peaking at 30 months. At the couple level, the experience of a death is multifaceted. Gender differences are common and partners' needs may change over time. Early recognition of differences may facilitate longer-term adjustment for both partners.	
24	Samuelsson, M, Rådestad, I, & Segesten, K (2001)	To describe how fathers experienced losing a child as a result of intrauterine death	11 men who had experienced intrauterine death (32 -42 weeks of pregnancy) 5-27 months before	interviews	Phenomenological analysis	After being informed about infant's death, most fathers wanted their partners to have a cesarean section, but all later felt it was ok for child to be delivered vaginally. Frustration and helplessness came over them during and after delivery. Several men found menaing and relief in their grief by supporting their partner. Tokens of remembrance from child were invaluable, and fathers appreciated staff who collected them for them. Some fathers missed having a man to talk to at time of stillbirth. The fathers' general trust in life and the natural order was suddenly and unexpectedly severely tested by the death of their child, which they perceived as a terrible waste of life. They sought understanding as grieving men and fathers from both the hospital personnel and their	Sweden

						partners, as well as from relatives. Being able to protect their partner and to grieve in their own way was important to the fathers		
25	Toedter, L., Lasker, J., & Janssen, H.(2001)	To compare and evaluate reliability in findings and the use of the perinatal grief scale in international studies	22 studies from 4 countries		Cross-cultural comparison of a standardized grief scale	Significantly higher scores were found in studies that recruited from support groups and self-selected populations rather than from medical sources and from US studies compared with European ones		US, Netherlands, UK and Germany
26	Rich, D.,E. (2000)	To determine the impact of postpregnancy loss services on grief outcome	249 bereaved mothers, 114 male partners (gestational age of 2-42 weeks)	Mailed questionnaire and the perinatal grief scale	3 stage multiple regression analysis	Predictors differed by gender and services contributed to prediction of grief outcome above and beyond demographic variables. Significant predictors for fathers were length of pregnancy, talking with friends, and timing of talking with family		US
27	Ujda, R.M. & Bendiksen, R. (2000).	to determine whether health care provider support has a positive, or helping, effect on the parents' grief resolution	Six men and thirty-four women as well as a focus group of six volunteers from the original set of forty persons experiencing perinatal loss.	Questionnaire and focus group	Qualitative analysis (content analysis)	Parents in the study put a high premium on the acknowledgment of their feelings by health care professionals. The latter group needs to know that although their support may not necessarily lessen the grief that parents may have, what they say and do at the time of loss is remembered and held in the hearts of parents. Their opinions may be repeated and reacted to often.	two obstetrics/ gynecology departmen ts, two family practice departmen ts in two medical centers, as well as five satellite family practice	US

	word for word, by mother and father to each other and to family and friends. Health care providers' words can take on more importance than the speakers could ever imagine.
20	

The psychological impact of the death of the baby was the focus of 11 studies which described grief, PTSD and discord in mother/father partnerships. The focus for improvement in care and support for fathers was emphasised in four studies. Three studies focused on the general availability of support and the extent to which fathers' grief was acknowledged. Five studies focused on the way men identified as fathers as well as experiences of grief. Of the reviewed studies, 11 focused on stillbirth and neo-natal death (compared with 11 studies which focused primarily on stillbirth). One study focused primarily on neonatal deaths. Study methods of reviewed articles varied: eight were quantitative; eight were qualitative; and one used mixed methods.

A further six articles were systematic reviews (two quantitative and three reviews of mixed methods studies). The remaining one was a meta-synthesises of quantitative, qualitative and mixed methods studies. The majority of data gathered was largely retrospective involving surveys, documentary analysis of patient records and interviews with families and clinicians.

Five main themes were generated with a focus on the impact of perinatal death for men and associated coping strategies, their role as fathers and partners and the extent to which this mediated their identity as a parent following the death. The availability of care and support by health and social care professionals was also an important factor in mediating men's response to loss.

# 4.1 The psychological impact of loss

The quantitative studies examined were focused on measuring the impact of parental grief following stillbirth and identified the effect of loss in terms of symptoms associated with grief which included PTSD, anxiety, depression, impact on couple relationships and differences in mothers' and fathers' levels of grief (Badenhorst et al., 2006; Büchi et al, 2007; Christiansen et al., 2014; Toedter et al., 2001; Vance et al., 2002). Most of these studies used standardised measurement tools, in particular, the Perinatal Grief Scale (PGS) (Toedter et al., 2001).

Säflund and Wredling (2006) examined 22 bereaved parents' psychological well-being 3 months after the stillbirth of their child and found that mothers scored higher on negative well-being than did fathers. Of these mothers, a majority remained on sick leave but all fathers returned to work. This is in keeping with the findings of other studies which found that fathers' experience of anxiety and depression following stillbirth and neonatal death were reported as being less severe than in mothers (Christiansen et al 2013; Badenhorst et al, 2006; Büchi et al, 2007; Turton et al, 2006).

Other authors have examined the psychological impact of stillbirth by reviewing several studies. A systematic review of 240 studies conducted by Burden et al. (2016: 4) found that stillbirth was associated with depressive and other negative psychological symptoms which included anxiety disorder, social phobia, agoraphobia, anger, negative cognitive appraisals such as a sense of failure and guilt as well as suicidal ideation and PTSD. Some parents reported social isolation and a disconnection from their social environment due to avoidance strategies and disenfranchised grief – parents became socially isolated by avoiding coming into contact with other babies or any situations where they could potentially be reminded of their own loss.

They were further isolated when their identity as a parent went unrecognised. Men reported marginalisation and a lack of acknowledgement as a grieving father. Men also reported distress when their baby was referred to as 'replaceable'. (Burden et al., 2016). The review reported that fathers described less intense anxiety and depressive reactions compared to mothers while fathers more often used alcohol to cope (Ward, 2012).

Christiansen's (2017) findings from a systematic review of 46 studies on perinatal loss found that parents interpreted the death of their baby as a highly traumatic event. However, the impact of loss as measured by the prevalence of PTSD differed between mothers and fathers: PTSD prevalence for mothers across the studies varied between 0.6% - 39% but for fathers it varied from 0% - 15%. Five studies in Christiansen's review found that mothers reported18 significantly more PTSD symptoms than fathers up to 18 years after the loss (Christiansen, 2017: 64). PTSD symptoms were not found to differ significantly according to whether the death occurred prior to, during or following birth and nor was gestational age associated with PTSD severity. The size of the population included in the studies ranged from eight to 634. Mothers were generally better represented than fathers with 64.5 percent of studies being solely based on mothers and 6.5 per cent based only on fathers, the remainder focused on couples. It is worth noting, however, that even within the studies which considered couples, mothers were better represented. Mothers, then, are overrepresented within studies on PTSD and other psychological symptoms of grief post infant loss (Badenhorst et al., 2006; Turton et al., 2006, Vance et al., 2002).

Christiansen (2017) has suggested multiple explanations for gender differences in the prevalence of PTSD following perinatal death. One is that parents are confronted by different social environments following the loss. The void left by the absence of a baby within a home may be greater for mothers as they may have spent more time preparing for the baby's arrival and take longer to return to work. This exposes women to more reminders, intrusive thoughts and may lead to more avoidance strategies (2017: 65). Moreover, the measures used to assess PTSD symptoms may fail to fully

capture paternal experiences of grief. Lastly, fathers may be expected to be strong and support the mother which may result in the underreporting of symptoms or the seeking of professional support. Consequently, fathers' grief seems less prevalent, less visible and is often overlooked by researchers, healthcare professionals and clinicians (Christiansen, 2017).

# 4.2 Claiming paternal identity

Men's identification with fatherhood is demonstrated in Bonnette and Broom's (2012) Australian, qualitative study of men's accounts of loss following stillbirth. Their study demonstrated some of the ways in which men identified themselves as a father to their unborn child and which continued after their baby's death.

Pregnancy was a key initiation into the father-child relationship and development of their paternal identities. Ultrasound scans during pregnancy were a significant event: hearing the baby's heartbeat and seeing the baby's body provided a sense of attachment (Bonnette and Broom, 2012: 254). Such representations played a major role in validating fatherhood status. Identification with their unborn child was extended to non-technologically mediated everyday rituals in which fathers would talk to the child and touch the 'baby bump.' (Bonnette and Broom, 2012). However, a common and contested theme from men's accounts was that women were culturally positioned as being more connected with their child because of pregnancy and childbirth. Yet, as Bonnette and Broom (2012: 256) argued, this fails to acknowledge that men as well as women described interacting with their deceased child in similar ways such as holding and bathing their child, talking with them and taking photographs. This was considered to be critical in enabling men to further identify themselves as fathers and continued long after their baby had died: several men continued to parent by talking with their deceased child or engaging in commemorative rituals such as lighting candles on the anniversary of their baby's death (Bonnette and Broom, 2012).

While Bonnette and Broom's study demonstrated some of the ways fathers identified with their child, the majority of studies revealed that father's identity and grief is overlooked (Kavanaugh et al., 2004; McCreight, 2004; O'Leary, 2005; Samuelsson et al., 2001) which resulted in diminished selfworth (Kavanaugh et al., 2004; McCreight, 2004; O'Leary, 2005).

Indeed, having children was seen by men to be an important dimension of being 'normal' and the stillbirth led men to give up future hopes, expectations and fantasies about the child and having a family (Cacciatorre, 2013 a; Mc Creight, 2004; O' Leary, 2005). It is clear that men are greatly affected by the stillbirth of their baby, perhaps reflecting the increasing social importance of fatherhood as a key component of contemporary masculine identities (Robb, 2004).

### 4.3 Fathers' expression of grief

The lower levels of grief reported by fathers in many quantitative studies can be interpreted as an example of 'grief suppression' (Burden et al., 2016) as fathers internalise their grief as a result of a sociocultural understanding of masculinity which expects men to be stoic and supportive of their partners. Similar conclusions are drawn by Cacciatorre et al., 2013, Cacciatorre, 2008b) who found that men's pronounced need to repress their grief can render them unemotional. Indeed, the incongruence of mothers' and fathers' experiences of perceived distress following the death of a baby is reported as being a critical factor in the development of relationship difficulties (Burden et al., 2016; Cacciatorre, 2008b).

Sociocultural ideas about masculine and feminine forms of emotional expression reflect binary notions of gendered forms of expression. Such stereotypical ideas suppose that women are passive and emotional while men's traits are considered as being stoic and inexpressive (Bonnette and Broom, 2012). One of the consistent findings of research on gender is that men tend to be less emotionally expressive than women, with dominant social expectations around masculinity causing many men to regard the open expression of emotion as 'unmanly', leading to a reluctance to seek professional help when problems arise (Robb and Ruxton, 2018). This is despite research showing that many men, particularly those on low incomes, experience depression in the transition to fatherhood (Wee et al., 2010). Such cultural scripts are evident in men's accounts of loss in several qualitative studies (Bonnette and Broom, 2012; Kavanaugh et al., 2004; Cacciatorre et al., 2013; McCreight, 2004; O'Leary, 2005; Samuelsson, 2001). Indeed, Bonnette and Broom's (2012) study demonstrates some of the ways men negotiated being 'manly', and expressing grief as a father identification as a father involved an emotional connection to their stillborn child yet, the performativity of masculinity required that they censor emotions. Phrases such as 'keeping it together' and 'holding it together' reflected a cultural expectation that men remain strong and stoical (Bonnette and Broom, 2012: 258).

Bonnette and Broom (2012) argue that while this reflects social expectations about gendered emotional responses to loss, it also reflects the moral economies of caring and dying. That is, caring is an embodied moral practice in which men are obliged to take care of their partners by enduring their own inexpressiveness of grief (Bonnette and Broom, 2012: 259). Enacting masculinity involves self-regulation with the men in Bonnette and Boom's study expressing grief and vulnerability when they were alone.

Consistent with Bonnette and Broom's research, McCreight (2004) reported that Northern Irish men put their own grief and emotional needs aside in order to support their partner. She also noted that several men had the onerous responsibility of being the person to inform family and friends and arrange a funeral, a task for which many men were unprepared. For several men, this was their first experience of death and one which they felt a sense of helplessness and despair.

A central theme in the research of men's accounts of loss was the social pressure to be 'strong' which created a tremendous burden and barriers to securing much needed support (Kavanaugh et al., 2004; O'Leary, 2005; Samuelsson et al., 2001). While some studies suggested that fathers should not be pushed into the supportive role (Badenhorst et al., 2006) others posited that this supportive role was meaningful and brought some measure of relief from their grief (Samuelsson, et al., 2001).

# 4.4 Fathers' support needs

Being recognised and validated as a grieving father and not merely as supportive partner was an important component of men's experience of perinatal death (O'Leary, 2005). Several studies reported that fathers felt diminished when concerns about loss were directed only to women, and as a consequence have felt disregarded by family and the healthcare system (Bonnette and Broom, 2012; Ellis et al., 2016; Samuelsson et al., 2001). This led men to challenge the notion that a partner's grief was more legitimate than their own (Bonnette and Broom, 2012).

In subsequent pregnancies men's support needs continued and fathers were challenged when trying to find ways to grieve, since their focus was once more on supporting their partner and this induced anxiety. As with their expectant partners, they found it difficult to engage in attachment behaviours with their unborn child in anticipation of another loss and consequently experienced considerable guilt (Campbell-Jackson et al., 2014).

Contrary to research that suggests men experience less distress following perinatal death compared to women, some studies suggest that men do experience a profound sense of loss (Cacciatorre, 2013; McCreight, 2004). Increasingly, men have turned to online internet sites to both describe and discuss their experience of grief: these postings highlight the biographical disruption experienced both at the time of the loss and throughout fathers' lives (Davidson and Letherby, 2014). As with mothers, fathers' accounts are vulnerable to being 'trolled' by others who disrupt online conversations to sow discord in an attempt to provoke an emotional reaction.

The level of support that men require is dependent on the support they receive elsewhere in their social networks (Erlandsson et al 2011). Support from family and friends is reported as being important up to two years after a stillbirth (Erlandsson et al., 2011). Kavanaugh et al. (2004) found that most bereaved parents sought support from within their family and mothers were more likely to seek support than fathers.

Why are grieving fathers less likely to seek support? Kavanaugh and colleagues (2004) suggest that this indicates that their experience of loss is misunderstood by family, friends and their work colleagues. High levels of distress *are* experienced by fathers, yet what helps to protect and sustain them are high-quality specific support interventions in hospital post-loss which respect the individuality and diversity of parental grief and respect for the child (Flenady et al., 2014). While healthcare providers acknowledge that fathers need to be included and considered in post-loss care, there is a lack of consistency in how this is delivered (O'Leary, 2005). As Flenady and colleagues (2014:138) point out in their international study on stillbirth, a baby's death is considered a taboo subject in hospital and considered unequal in human value to the death of an older child. This has implications for paternal support needs and in particular, the extent to which their grief remains disenfranchised (Cacciatorre et al., 2008).

## 4.5 Support and care by professionals

In this review we evaluated studies which focused upon parents' and healthcare professionals' experiences of care after perinatal death (i.e. Badenhorst et al., 2006; Erlandsson et al., 2011; Ellis et al., 2016; Kingdon et al., 2015; Säflund and Wredling, 2006) which has been identified as impacting upon grief outcomes (Erlandsson et al., 2011; Rich, 2000; Udja, 2000). Several studies called on professionals to acknowledge paternal grief and to recognise that they are much more than 'supporters' and 'comforters' of their partners (McCreight, 2004). Studies indicate that fathers value person-centred, psychosocial care (Cacciatore et al., 2013). One study found that fathers appreciated staff who collected 'tokens of remembrance' of their infant who had died intrauterine (Samuelsson et al., 2001). Others highlighted the important role professionals play in helping parents make decisions such as holding their deceased child (Kingdon, et al., 2015; Wilson et al., 2015).

The practitioner role is also identified as being crucial during subsequent pregnancies for helping parents to manage their fears and anxieties. O'Leary (2005) suggests that health care practitioners should consider PTSD symptoms to be a normal phenomenon during ultrasound examination as distressing memories can be expected to occur during this time. Indeed, fathers as well as mothers report psychological distress in subsequent pregnancies and at the prospect of the birth of a

subsequent child (Campbell-Jackson et al., 2014; Turton, 2001). Indeed, findings highlight the importance of tailoring support systems according to both maternal and paternal needs.

### 5.0 Discussion

Overall, this review found several themes that have reported regarding men's experiences of stillbirth and neo-natal death. Findings indicate that men feel they need to take on a supporter role for their female partner which may be detrimental to their own health and well-being (Bonnette and Broom, 2012; McCreight, 2004; O'Leary, 2005). The studies also demonstrate that the death of a baby leads to a loss of identity as father (Bonnette and Broom, 2012). Moreover, the review found that stillbirth and neonatal death is associated with a lack of social recognition leading to disenfranchised grief for men, in addition to the challenges they faced in accessing support which also had deleterious consequences (Ellis et al., 2016; Samuelsson et al, 2001).

While the feelings associated with stillbirth and neo-natal death are similar for men and women, the expression of these feelings differ, indicating that men's health and wellbeing is an important area of research. Indeed, the lack of knowledge of these issues amongst some health professionals and family members can lead to helplessness, marginalisation and feelings of loneliness during grief (Ellis et al., 2016; Samuelsson at al., 2001). Many studies focussing on stillbirth and neo-natal death have inferred that men's behaviour is due in part to a social-cultural belief that men may be less willing to communicate and express grief and that the impact of loss is far greater for women than men (Badenhorst et al., 2016; Büchi et al., 2007; Christiansen et al., 2014; Toedter et al., 2001; Vance et al., 2002).

There are also methodological issues. Men have tended to be interviewed as part of a couple and those studies which focus specifically on men have some issues with generalisability due to their focus on stillbirth experiences, small sample sizes, and sampling methods (Campbell-Jackson et al., 2014; Kavanaugh et al., 2004; McCreight, 2004; O'Leary, 2005; Samuelsson, 2001). This suggests that in taking part in research, the men interviewed have a vested interest in their health and well-being and may not be representative of the general population of men who are experiencing grief following perinatal death.

Another common theme evident in studies is of men's responsibility in being a supportive partner who needs to remain strong despite their own experience of loss (Bonnette and Broom, 2012; Cacciatorre et al.. 2008b; Flenady et al., 2014). As a consequence men may not feel fully able to disclose their feelings for fear of appearing weak and vulnerable and have reported increased substance use, and employment difficulties (Burden et al., 2016; Bonnette and Broom, 2012; Ellis et al., 2016; Mc Creight, 2004). Some men have turned to the internet to both find other accounts of grief which resonate with those of their own accounts of loss, hopelessness and despair (Davidson and Letherby, 2014).

The findings from this study has implications for practice by health professionals. The care and support provided by health professionals influenced father's responses to their loss with some men feeling marginalised (Erlandsson et al., 2011; Rich, 2000; Udja, 2000). Several studies argued for the need for professionals to acknowledge paternal loss and the role of men as more than that of a 'supportive partner' (Erlandsson et al., 2011). Indeed, several men were unprepared for the tasks assigned to them such as telling family and friends of the death (Cacciatore et al., 2013).

Moreover, the findings demonstrate the need for all health professional to invite fathers and mothers to engage in appropriate rituals such as holding the baby and collecting memorabilia (photographs and handprints) to validate feelings and experiences of men. When men received empathic care and support by professionals, they felt their grief was validated.

Despite the development of guidelines by organisations such as SANDS to support parents, it is not known to what extent, health professionals pay heed to them or if they have the time and resources to utilise them effectively in practice. Adherence to guidelines and best practice is a neglected area for health professionals in the context of bereavement support following perinatal death and future research around perinatal loss should address such a critical question.

# 6.0 Conclusion

The findings of this review can be considered fit for purpose for health professionals and organisations seeking to obtain knowledge of men's experience in order to develop the means to support them (Grant and Booth, 2009). Moreover, this review has identified future research priorities by identifying the gap in the literature, and potential for future research which might focus around men's health and wellbeing following perinatal loss. However, this review recognises the potential for bias because of the limitations in rigour and that the conclusions are based on the studies available for review as opposed to the quality used to generate conclusions in keeping with a systematic review (Grant and Booth, 2009). Nevertheless, this scoping review has identified

implications for practice and can inform policy makers whether or not a full systematic review is

needed (Grant and Booth, 2009; Levac et al, 2010; Peterson et al., 2017).

The scope of the review was on stillbirth and neo-natal death, however, more articles were found

and included on stillbirth than on neo-natal death which reflects the paucity of current literature on

men's experience of neo-natal death. Therefore, a quality screening was not undertaken due to the

heterogeneity among studies. Future studies may be able to utilise meta-analysis to examine the

impact of loss for men in more depth.

Future research should focus on men's health and well-being rather than the psychological impact.

Studies which have focused on the psychological consequences for men have tended to employ

measurements which do not fully capture men's experiences of loss. The development of a

psychometric tool which includes non-psychological aspects of men's experience could be used to

measure a larger sample and therefore be more generalizable. Indeed, it is important to

acknowledge the impact of avoidance and coping behaviours that men adopt as a result of loss

including alcohol misuse and employment difficulties and the impact this has on bereaved couples'

relationships. Differing experiences of loss can lead to a relationship breakdown, further

exacerbating men's grief responses.

Larger studies of men from various cultural backgrounds could be helpful to demonstrate how the

impact of loss can differ in relation to culture and how societal expectations of grieving behaviour of

men influences the expression of grief. Culture is important since it can provide a framework in

which to demonstrate the way in which parents ascribe meaning to the loss of their baby and the

way in which men cope with grief in their specific cultural contexts.

Finally, it is important to further explore men's experience of stillbirth and, in particular, neonatal

death to provide a better understanding of how stillbirth and neo-natal death impacts upon men's

mental and physical well-being, and which may influence the development of improved practices by

health professionals.

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